POLICIES AND PROCEDURES FOR RELEASE OF VITAL RECORDS INFORMATION

Missouri State Statutes and Code of Regulations allow for the release of record level vital records data by the Missouri Department of Health and Senior Services. The statutes below only apply to vital events occurring within Missouri's borders. The records of vital events that occur to Missouri residents in other states are the property of the state where the events take place.

193.045.2(4), RSMo, authorizes the state registrar to provide to the state or local health agencies copies of or data derived from certificates and reports required under sections 193.005 to 193.325, deemed necessary for state or local health planning and program activities...such copies or data shall remain the property of the department and the uses made of them shall be governed by the state registrar.

193.245(1), RSMo, the department to disclose upon request, a listing of persons who are born or who die on a particular date, but no information from the record other than the name and date of such birth or death shall be disclosed.

193.245(2), RSMo, Allows the department to authorize disclosure of information contained in vital records for legitimate research purposes.

193.255.4, RSMo, authorizes the state registrar, upon request by federal, state, local and other public or private agencies, to furnish copies or data of any other vital statistics... for statistical or administrative purposes upon such terms or conditions as may be prescribed by regulation, provided that such copies or data shall not be used for purposes other than those for which they were requested unless so authorized by the state registrar.

19 CSR 10-10.090 Access to Vital Records: (1) (B) 3. No data shall be furnished from records for research purposes until the state registrar of vital records has received and approved a formal request for the research project. (1) (B) 2. The term research means a systematic study designed to develop or contribute to generalizable knowledge. The term generalizable means to emphasize the general character rather than specific details of, to formulate general principles or inferences from particulars. (1) (D) authorizes the state registrar or the local custodian – when deemed in the public interest and not for purposes of commercial solicitation or private gain – to furnish copies of records or data from records to public agencies administrating health, welfare, safety, law enforcement, education or public assistance programs and to private agencies approved by the state registrar.

Vital Records requesters for research or administrative purposes will only be provided access to information necessary to address their specific research or administrative questions. They are prohibited from disclosing any information that would identify a person and are also prohibited from the re-release of the data provided.

Under section 610.035, RSMo, the department is prohibited from disclosing any Social Security number of a living person unless such disclosure is permitted by federal law, federal regulation or state law. Section 208.120, RSMo prohibits the department from disclosing any information obtained by them in the discharge of their official duties relative to the identity of applicants for or recipients of benefits or the contents of any records (e.g., Medicaid, WIC, Food Stamps). Public service information can be provided on de-identified records only.

For births de-identified records are those records having the following data elements blanked out:

Child's name

Day of month of birth

Mother's name including maiden name

Mother's date of birth (replaced with age)

Residence Address below county level

Latitude & Longitude

Father's name

Father's date of birth (replaced with age)

Child's Medical ID Number

Mother's Medical ID Number

Child's DCN

State File Number

Birth Attendant License

Missing Child Indicator

Paternity Affidavit

Paternity Establish date

For deaths de-identified records are those records having the following data elements blanked out:

Decedent's Name

Decedent's Date of Birth

Decedent's Date of Death (replaced with age)

State File Number

Surviving Spouse Name

Residence Address below county level

Latitude & Longitude

Decedent's Family Name

Funeral Facility Number

Attendant License Number

Other Name

Application for Record Level Vital Records Data

Any request for record level data (whether identified or de-identified) shall require the completion of the 'Protocol for Study/Project Using Missouri Vital Records' located at: http://www.dhss.mo.gov/data/doc/protocolform.dot. If the research/project involves linkage with another data set or contact with family, next-of-kin or acquaintance then Department of Health & Senior Services (DHSS), Institutional Review Board (IRB) approval is also required. A request for identifiable record level data for living subjects (e.g., birth records) shall also require approval by the DHSS IRB. Requests for de-identified files do not require approval by the DHSS IRB. The following forms must be completed for an IRB approval:

Abstract of Protocol

IRB Form 1 'Request for Review of Research Protocol'

Protocol Template

Checklist for Submission of Research/Study Protocols

These are available online at: http://www.dhss.mo.gov/data/irb/.

The 'Protocol for Study/Project Using Missouri Vital Records' should include a summary of the research protocol or the administrative purpose for which the data will be used. Also, describe the confidentiality protections to be employed. The applying agency must give assurances that:

- 1. No other agency or individual will be given access to the provided file or an abstract thereof where individuals can be identified in any manner. If the data are maintained on a computer or computer media, proper security measures must be in place to protect against other users.
- 2. The data will be properly disposed of once the relevant information has been obtained, and the State Registrar notified in writing of such disposal.
- 3. No attempts will be made to contact family members or acquaintances of decedents or infants unless written permission has been obtained from the State Registrar and the DHSS IRB.
- 4. No attempt will be made to link with other data files unless the linkage is addressed in the 'Protocol for Study/Project Using Missouri Vital Records' and approved by the State Registrar and the DHSS IRB. DHSS IRB approval is not needed for linking death files with other files as long as there is no contact with next-of-kin.
- 5. The use of these data will be restricted to the proposed purpose. Any newly conceived uses require a new 'Protocol for Study/Project Using Missouri Vital Records' and must be cleared through the State Registrar and IRB if applicable.

Review Process

The State Registrar along with the Bureau of Health Informatics will review the protocol. This review will be based on the following factors:

- 1. Whether the study/project is adequately defined and has merit for public health
- 2. Adequacy of confidentiality measures
- 3. Availability of resources to complete the request

If the request is denied, the requesting agency will be notified in writing of the reasons for denial. If insufficient documentation is presented to determine approval, additional information will be requested to clarify the application.

Transmission of Data to Requesting Agency

If the request is approved, the manner of transmission will depend on the type of data to be received. In all cases of approval, payment is expected prior to the department completing the request. The three types are:

- 1. Vital Record Certificates—There is an assessed charge per certificate. The Bureau for Vital Records will inform the requesting agency of the number of certificates involved and the cost. A check for the appropriate amount should be made payable to the "Missouri Department of Health and Senior Services" and submitted to 'Missouri Department of Health and Senior Services, Attention Fee Receipts'. The certificates will be forwarded as soon as possible after receipt of the check.
- 2. Computer Media—A research analyst within the Bureau of Health Informatics will discuss with the requester the type of computer media needed and inform the requester of the cost. A check for the appropriate amount should be made payable to the "Missouri Department of Health and Senior Services" and submitted to 'Missouri Department of

- Health and Senior Services, Attention Fee Receipts'. Once the research analyst has been notified that payment has been made, the request should be completed within two weeks depending upon circumstances.
- 3. Computer Printout Lists--- A research analyst within the Bureau of Health Informatics will notify the requester of the cost. A check for the appropriate amount should be made payable to the "Missouri Department of Health and Senior Services" and submitted to 'Missouri Department of Health and Senior Services, Attention Fee Receipts'. Once the research analyst has been notified that payment has been made, the request should be completed within two weeks depending upon other circumstances.

Complete, sign and date the 'Protocol for Study/Project Using Missouri Vital Records' and the IRB forms if applicable and submit all the forms to:

Bureau of Health Informatics Missouri Department of Health & Senior Services PO Box 570, 920 Wildwood Drive Jefferson City, MO 65102-0570 - Or -Fax to: (573) 526-4102, attention Dawn Parker

Please also submit an electronic copy of the forms to: <u>Dawn.Parker@dhss.mo.gov</u>. No signatures are required for this electronic copy.

Related Information and Forms

Vital Records Rule

Protocol Letter

Protocol Form

Institutional Review Board Guidelines and Forms

Data Fee Policy